

DOCUMENT RESUME

ED 288 334

EC 201 215

AUTHOR Adam, Heidemarie; Gudalefsky, Adam B.
TITLE Sexuality and Mental Retardation [including] "Ethical Issues Concerning Mentally Handicapped Persons."
PUB DATE Aug 86
NOTE 49p.; Paper presented at the World Congress of the International League of Societies for Persons with Mental Handicap (9th, Rio de Janeiro, Brazil, August 21-29, 1986).
PUB TYPE Speeches/Conference Papers (150) -- Reports - Descriptive (141) -- Viewpoints (120)
EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Adults; Attitudes; Bias; Ethics; Foreign Countries; Instructional Materials; *Interpersonal Relationship; *Mental Retardation; Moral Values; Normalization (Handicapped); Residential Programs; *Sex Education; *Sexuality
IDENTIFIERS West Germany

ABSTRACT

The paper documents two presentations made during a pre-congress course of the Ninth World Congress of the International League of Societies for Persons with Mental Handicaps. The course, titled "Sexuality and Mental Retardation," was held in August 1986. Part I discusses the topic's theoretical aspects, such as moral perceptions of sexuality, the possibilities opened up by normalization, and prejudices and misjudgments made concerning mentally retarded individuals' sexuality. Part II of the first presentation reports on the development of relationships between West German institutionalized men and women when the concept of mixed-sex living was introduced. Suggestions for sexuality education programs for the mentally handicapped focus on body image, appropriate behavior, puberty, pregnancy, and childbirth. Sample instructional materials accompany the paper. The second presentation, included in an appendix, consists of a paper by A. Gudalefsky titled "Ethical Issues Concerning Mentally Handicapped Persons." The paper relates ethics to the nature of human society, cites United Nations documents dealing with the rights of the handicapped, and discusses issues such as the handicapped's right to life and right to education. (JDD)

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9.th World Congress of the International
League of Societies for Persons with
Mental Handicap (ILSMH)

Rio de Janeiro, Brazil, August 21-29, 1986

"Together we can do it"

Paper delivered at the

Pre-Congress Course:

Sexuality and Mental Retardation

(held Aug 21 - Aug 23)

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EC 201215

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Preface

At the 9.th World Congress of the International League of Societies for Persons with Mental Handicap (ILSMH) in Rio de Janeiro, Brazil, August 21 to 29, 1986 I have been conducting a Pre-Congress Course on the theme "Sexuality and Mental Retardation" August 21 to 23, 1986. More than hundred people participated in this course.

My presentation which is documented on the following pages was delivered in portions and thoroughly discussed. This resulted in further explanations in the discussions.

Since the whole question can't be properly discussed without the ethical issues involved, I invited Father Adam B. Guadalefsky, M.M. from Hong Kong to join me in this Pre-Congress Course, which he did. I am glad that he agreed to have the paper he presented on "Ethical issues concerning mentally handicapped persons" included in this publication. Therefore you'll find it added to my paper.

May our thoughts be helpful for persons dealing with the topic of "Sexuality and Mental Retardation."

Dr. Heidemarie Adam

Sexuality and Mental Retardation

O. Approach to the theme

O.1. A quick look into the past

In 1968, I started working as a teacher at the "Hessischen Diakoniezentrum Hephata", which is a school for the mentally retarded in Hessen, a state in West Germany. This institution was established over one-hundred years ago. It was founded by an order of deacons who wanted to help ease the misery of handicapped persons and their families. Characteristic of the moral ideas of the time, there were houses exclusively for men and boys, and others for women and girls. The deacons themselves worked exclusively in the houses for male residents. In the houses for female residents, the administration and care was carried out by women. Very close attention was given to make sure that as little contact as possible would occur between the men and the women. The following picture could still be observed at Hephata when I began working there: A group of ladies would leave the "Bethany-House" with a staff person and would come across the path of a group of men from the "Emmaus-House" under the supervision of one of the deacons. As soon as one of the group leaders would notice that they were nearing each other, they would quickly turn and begin to walk in opposite directions.

A consequence of this strict separation was homosexuality both among men and among women. Restraint of this form of sexuality was attempted as well. However, eyes have often been closed to what, in large common bedrooms, could not be prevented anyway. Many professionals believe as well that persons who are mentally retarded are not capable of developing heterosexual relationships. Therefore, the desire for homosexual contact of persons who are mentally retarded was thought of as normal.

O.2. Personal experiences

Just before I began working at Hephata, I gave birth to my first child. My fifteen to eighteen year old pupils were fascinated with my baby. Therefore, I invited them to my home and we fed and bathed the baby together. I asked the pupils more in fun than seriously, if the baby was a boy or a girl. After my kicking naked son was scrutinized for a while, a couple of pupils decided that it could be a girl, judging from the baby's face. I was amazed. I really had not expected this. It appeared that these pupils had no idea at

all which physical characteristics distinguish boys and girls from each other.

This experience brought the problem to my attention but led to no changes in what was taught. With five years of existence, the school for the mentally retarded was the newest form of special school. We teachers had to develop lesson plans and devise our own methods of teaching. We wanted to facilitate certain social competencies that were most appropriate for our pupils to learn, and asked ourselves what the best way would be to teach a child to blow his nose. Sexuality education was not our problem. We had the opinion that this was a job for parents and care-providers.

Two years later, I was expecting my second child. My class of ten year olds took a lively interest in the gradual enlargement of my abdomen. To my relief, the pupils were neither interested in how the baby got there nor thought about how it would come out. They were more fascinated by the fact that the baby would one day live with me, as they were institutionalized children who missed their parents terribly. One of the boys tried to solve this problem in the following way. He explained, "I will climb into your belly and when I come out again, I will be your child." Although I had not to answer the questions how I became pregnant I found it very problematic to explain why I did not want to take my pupils home and become their mother.

With this, I believe the ensuing questions are clear enough. I will treat the theoretical aspects of the theme in the first part of my execution, and in the second part, I will deal with practical questions about sexuality education for persons who are mentally retarded.

Part I: Theoretical Aspects

1.1. Explanation of terms

1.1.1. Mental Retardation

The American Association on Mental Deficiency (AAMD) defines mental retardation in the following way, "Mental retardation refers to significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period." (Grossmann, 1973,5)

According to this definition, only those who test at least two standart deviations below the mean of an IQ test, are considered

mentally retarded.

<u>Degree of Retardation</u>	<u>Range of IQ Test-Score</u>	
	Binet Stanford Cattell	Wechsler
Mildly retarded	61-52	69-55
Moderately retarded	51-36	54-40
Severely retarded	35-20	39-25
Profoundly retarded	19 and less	24 and less

In 1983, this table was revised in the following manner.

(Grossmann, 1983, 13)

<u>Degree of Retardation</u>	<u>Range of IQ Test-Score</u>
Mild mental retardation	50-55 to approx. 10
Moderate mental retardation	35-40 to 50-55
Severe mental retardation	20-25 to 35-40
Profound mental retardation	Below 20 or 25
Unspecified	

Seldom in practice, would such a separation of the degree of retardation be possible. However, when we are talking about a type of person, it is important to know to what degree they are handicapped, to have a basis for referral.

1.1.2. Sexuality

When we are discussing the sexuality of persons who are mentally retarded, we tend to think exclusively of genital sexuality. This discussion is quickly narrowed to the question, should they or should they not be allowed to ...? When the question is phrased in this way, it is usually answered in one of the following two ways.

- a.) Naturally, they should not be allowed to, because they are unable to live up to the demands of a child.
- b.) They may only be allowed to, if it is not done only in fun. They should be capable of being faithful to their partner. They should be in a position to fulfill all ethical norms inherent of the institution of marriage.

Both of the criteria are obviously only intended for those persons who are mentally retarded. With so-called normal people it is neither asked if they are in a position to raise children, nor is their relationship examined to see if it satisfies high ethical standards. Just the opposite in fact, we all know families who take poor care of their children. The children's homes in Germany are filled with children who have been neglected. Broken-up marriages that often lead to divorce are equally as well known to us. I will not take the position here that all persons who are mentally retarded

should have the right to marry. I would like to merely make it known that the reasons that are used to take away these privileges are not especially sound. Before this problem can be discussed any further, the term sexuality should be closely examined.

Sporken (1980, 19f.), a Dutch moral theologian subdivided the "General-complex" into a 3-step model:

1st Step

Sexuality encompasses all aspects of human life which play a role in determining whether one is a man or a woman, boy or girl. Almost always the birth of a son or of a daughter will bring out different sentiments. Expectations from parents and society show up in the clothing, preferred games, and in the development of the child's interests. Sexuality is linked inseparably with being human. The "I-identity" can only be gained through an affirmed membership in either sex group. Becoming aware of one's personality always includes becoming conscious of one's own sexuality.

If we agree with this, then it ought to be clear, that it is just as important for the mental development of persons with mental retardation, to be able to experience themselves as men or as women.

2nd Step

Naturally, the word sexuality encompasses a middleground of ordinary human relationships such as tenderness, sensuality, and eroticism. That is, all phenomena that strongly influence human life. The type of behavior that we display is often determined by the fact that we are in love or have a crush on someone. Because of desiring someone, we try to look our best and be especially nice so that we do not endanger a further loving relationship.

3rd Step

The third step relates to genital sexuality. The question of whether persons who are mentally retarded should or should not be allowed to, has already been dealt with. This subject will be treated more specifically in the second part of this delivery.

Where to draw the line between these three steps is naturally difficult, as they overlap. If one accepts the fundamental principle that man is a sexual being, one can not then erect such abrupt boundaries. Instead, he must accept the overlap of one range into the other. It is especially important to make it clear that there is no sequence to the three steps. The first is not any more valuable than the second or third, and should by no means be viewed



Friendship often means: Just to see each other day by day ...



... to smile at each other ...to help
one another. Who says: this isn't a partnership?

as negative. The divisions should merely help us not to tie ourselves down strictly to a certain point.

1.1.3. Partnership

In order to prevent thinking of sexuality of the mentally retarded purely in a genital sense, the word partnership has been introduced. In Hephata, the institution in which I worked for a long time, there was a working-team which had the goal of bringing about normalization in life relationships. So as not to be miscredited as a "Sex-club", they named themselves "Arbeitsgemeinschaft für die Verwirklichung partnerschaftlicher Beziehungen" (AG Pa Be) or in English, the working-team for the realization of partner - relationships. Anyone who dares to break new ground in this subject in his school or institution, should consider the choice of words such as these, to curtail misunderstandings. Many parents and care-providers react hysterically to the word sexuality, because they right away think of sexuality in the genital sense. It is possible to get them to alter their ideas enough to agree with accepting the first step, and at least become acquainted with the second step. It is very important for the lines of communication to be kept open. Therefore, unnecessary provocation should be avoided.

1.2. Altering moral perceptions

The education of children who are mentally retarded does not occur in a vacuum. They live in a certain society with a certain history and they must learn to find their way within it. If we take the case of eating habits, we can immediately observe this. In Germany, children must learn to eat with a knife, fork, and spoon. They should sit up straight at the table and should not tip their chairs back. In India, there are neither tables nor chairs in many homes. One sits on the floor and eats with one's fingers. It should then be apparent to us, that all children who are mentally retarded must learn to eat as their parents, brothers and sisters, and relatives.

The same must then occur with sexuality. Young people who are mentally retarded must learn to adapt the norm appropriate for a certain society, but this can be a ticklish subject. Although all would be ready to agree with me on this when speaking of eating habits, most would view this idea skeptically when referring to the sexual rights of handicapped and non-handicapped.

The principle of normalization applies to eating, clothing, living, and working. The question is whether this applies to love,

friendship, and partnership as well. In the past twenty-five years, moral perceptions have changed drastically. Older people still hold fast to conservative moral values. The younger people seem to believe that young persons who are mentally retarded should be given the same freedom as they themselves enjoy.

When I was twenty years old, a girl usually was a virgin when she married. Illegitimate children were tolerated but discriminated. Divorces were possible but divorced women were outsiders and were looked upon in a distorted way. In magazines, only heads of people were shown. A film in which a girl would be seen naked even for a few seconds was discussed fervently and considered a threat to our youth.

Within relatively few years, all of this has changed dramatically. Many professionals are of the opinion that the pill has brought about this change. If they should be correct, that would mean that earlier generations held back exclusively because they feared unwanted children.

Today every magazine has a girl in a bikini on the front page. Mothers are more and more allowing their daughters to obtain prescriptions for the pill as soon as they turn fourteen or fifteen years old. Young people consider it their right, to live with a boyfriend or girlfriend for years, without thinking of marriage at all. When they do not get along with each other any more, they simply find a new partner. It even happens, that women are refusing to marry the fathers of their children.

That is the situation. No one knows, if this new freedom is really an improvement or not. Professionals suppose that perhaps old dependencies were replaced by new ones. Maybe in twenty years we will know better but that does not help us at the moment. Now we must decide what possibilities can and should be opened up to persons who are mentally retarded.

1.3. Consequences of the principle of normalization

Since the formulation of the principle of normalization in Denmark and Sweden, aid to the handicapped in Germany has changed a lot. Persons with mental retardation should be allowed to live as normally as possible. As children, they should be allowed to play and go to school. Adults who are mentally retarded should be able to live as independent as possible. Living, working, and leisure-time should be similar to that of an ordinary citizen.

One effect of the principle of normalization was that we became more aware of the adults who are mentally retarded. All of a sudden, it was seen as inappropriate for a forty year old to be playing children's games. Finding age-appropriate work for these adults and altering their living-situation was attempted. Among other things, the care-providers began to address these adults using their last name, or they would exchange the use of first names.

Above all, the assurance was brought about that everything should not be, planned, and decided for persons who are mentally retarded. Those concerned should always take part in the decision process. In retrospect, we know, that much more is possible than we ever dreamt of.

From this angle, the question of which possibilities should be opened up to the mentally retarded is wrong. We being non-handicapped are not in the position to judge as experts, the feelings and desires of other people, based solely on their handicap. Herein lies the problem however. We as parents, care-providers, and teachers decide what we think is good and tolerable, and what is bad, and therefore must be thwarted. We talk about the mentally retarded rather than talking with them.

Our thoughts in general come from our own perceptions of love and partnership. Up until now, we have not thought much about what persons who are mentally retarded would desire from a partnership, what they would dream of, and how they would like to live. I therefore maintain, that the problem of sexuality of the mentally retarded is, in general, less of a problem for the persons who are mentally retarded themselves, but rather a problem for the care-providers and teachers. Our own biases abstract our view of reality.

Over and over again, when talking with parents of the mentally retarded, it appears that they think in one of two ways. Either they believe that their sons and daughters will remain eternally children and would have no sexual impulses or they fear that they may wake up to reality and would unavoidably develop into sexual mainacs. Both ideas are false. Young people who are mentally retarded develop very similiary to others of their own age. They must, for this reason, come to terms with their awakening sexuality, and exactly like other young people, must find a form in which they find order and contentment. This fact forces us not to leave the person who is mentally retarded without an advisor on sexuality, but instead

to offer him/her help in overcoming these problems. Before I describe how the idea of such an advisor could work out, I would like to consider in detail three prevalent prejudices.

1.4. Prejudices and misjudgements in relation to the sexuality of persons who are mentally retarded

1.4.1. The innocent child - or the denial and suppression of the sexuality of mentally retarded persons

For most people, sexuality and mental retardation are incompatible terms. A picture of a naive, innocent large, asexual child is characteristically expected when one thinks of a person who is mentally retarded. Unfortunately, special educators helped to perpetuate this concept, as for years this subject was skipped over and it was thought best to divert the attention of the retarded away from it. For this reason, the adult who is mentally retarded is forced into a difficult psychological position. In order not to take the risk of losing the social gratification of his parents and care-providers, that is so important for his personality development, he must behave as he is in fact an innocent and asexual overgrown child.

Out of the previous publications of sexual medicine, the following is consistently found. The physical sexual-biological development of maturity of mentally retarded children proceeds in most cases consistent with age and independent from intellectual factors.

It is clear that this situation could lead to conflicts that can not be overcome by the retarded themselves. Their already limited possibilities will be further restricted through this.

1.4.2. The sex maniac - or the dramatization and overemphasis of the sexuality of mentally retarded persons

Many people feel uneasy by the idea that the mentally retarded persons living in their neighborhood would have a similar sexual life as they themselves. They often assumed that persons who are mentally retarded are not in the position to satisfy their sexual urges in a socially acceptable manner. Therefore parents and caregivers often fear that sex education could awaken "the sleeping dog".

Huber, the director of a Roman Catholic institution for mentally retarded persons, explained this stereotype in the following manner: For a nonprofessional, the lack of intelligence includes the inability to integrate human sexuality into the personality. Out of this then grows the fear that sexuality for the mentally retarded is

unregulated and when left to develop on it's own, becomes aggressive.
(Huber, 1975,13)

Schröder, another author concludes ironically, "one expects that when the lurking energy of the mentally retarded is stirred up, that they will storm around unrestrained like sexual King-Kongs and threaten and endanger our nonhandicapped woman and children."

Stuck behind these prejudices is the fear of the actualization of their own strongly suppressed and denied sexual urges, which are then projected onto mentally retarded people. This may explain the rigorous harshness with which many parents and teachers treat sexual impulses such as masturbation, which is suppressed and punished. There is also a strong wish for sterilization of all mentally retarded girls before they are of confirmation age. This may have its root in the previously mentioned overdramatization of the sexuality of the mentally retarded.

1.4.3. The sticky closeness - or the misinterpretation of nonverbal communication of mentally retarded persons

May misunderstandings of forms of expression exhibited by persons who are mentally retarded have their origin in the lacking capability to express oneself through speech. They can only poorly make themselves verbally understood. Therefore, it is important for them to use mimic and gesture to express feelings and desires. Where terms and words are lacking, a person who is mentally retarded may try to express his/her feelings by snuggling up or stroking a person to whom he/she is speaking. These nonverbal forms of expression will often be misinterpreted by outsiders. They become disturbed and consider the mentally retarded to be uncontrollable or impulsive. Knowing the significance of the mentally retarded person's lack of speech expression, the main duty of parents and teachers should be to help them discover socially acceptable gestures and body positions. This will enable the person who is retarded to better differentiate between feelings and to understand them better. Just as those who are able to speak usually talk with strangers on the street, can the mentally retarded learn not to hug every stranger.

Persons with mental
handicaps often express
their affection through
nonverbal communication.
A language we often don't
understand.



Part II: Accompaniment of the mentally retarded

2.1. The example: Hephata

In this second part, I would like to share a report dealing
with the development of relationships between men and women in Hephata-

ta, the institution in which I worked. The principle of normalization started the ball rolling. Groups were made smaller, living opportunities were improved, and old forms of living together were carefully inspected. Many of the staff were in agreement, that long-term arrangements should be made in converting to mixed-sex groups. In order to prepare the way for the necessary changes of attitude and in order to plan ways in which the organization could be changed, the previously mentioned working-team, for the realization of partner relationships (AG Pe Be), was formed in 1977.

The AG Pe Be worked on solving the following problems:

1. Preparing for the idea of mixed-sex group living.
2. Developing a concept for a "meeting-point" where men and women should have the opportunity to meet informally after work.
3. Offering of a discussion group for mentally retarded couples.
4. Gathering of information on sexuality and mental retardation which should be made available to staff as well as to residents.
5. Organizing continuing education and seminars relating to this theme.

2.1.1. The "Meeting-Point"

In the beginning there was a lot of opposition to the new ideas. It was a big step forward when the "meeting-point" was started in the school building. Twice a week there was the possibility to spend some time with friends, play party games, and dance in a disco atmosphere. In the beginning, this disco was organized by teachers. They then tried to convince the administration that it should find someone to take over this responsibility. A social worker was hired twenty hours per week to take over this job. Later, this position was split, and today there are two social workers employed as leisure-time coordinators. Finally the "meeting-point" got old rooms in an old building. Now it could be furnished according to the young people's own taste.

The success of this "meeting-point" proved that persons who are mentally retarded could decide many things for themselves. First of all, they told us that we had picked out the wrong music. They brought their own records with them and even found their own disc-jockey. At every "meeting-point" afternoon, refreshments were offered for sale. This was an idea inspired by the residents and was organized by them. Drinks were selected, prices compared, and the margin of profit was established. Specific desires for certain foods offered were accommodated. Men and women from different groups were



Having fun at the "Meeting-Point"

involved in preparing salads, sandwiches, and so forth.

Surprisingly persons with severe and profound mental retardation were just as interested in these leisure time activities as young people with mild mental retardation. Even "normal" youth came and this sometimes presented a problem. On one side, this integration should have been welcomed. On the other side, however there was the danger that these youth wanted to set the tone of the meetings and sometimes would pick fights with the residents in order to raise their own self-confidence, at the cost of the retarded young people.

In spite of this, today the "meeting-point" is the magic word which easily brings together 200-250 people! There I got to know my first severely retarded couple. A young woman, barely able to move at all, nonverbal, and in fact we could not even tell how much she perceived from her environment, came quite regularly. She was immediately adored by a man with similar handicapping conditions. Both of them sat for hours at the table gazing at each other. Sometimes, they would carefully take each other's hand. Both had rosy cheeks, looked very happy and very much in love. At 10:00 everyone left and returned to their own group.

This "meeting-point" helped to change attitudes. Even the skeptics became convinced that persons who are mentally retarded do not flip out right away when they come together unrestricted and with little supervision. Couples now had a place where they could be together. Cold walks in the rain were now not the only possibility to get together. Men and women had the opportunity to get to know one another in their free time. Now friendships grew out of this.

2.1.2. The question of living accommodations

Last but not least, the positive experiences with the "meeting-point" helped us to realize the idea of allowing the differing sexes to live together. It all began with a group of children.

This liberalization was noticed by the residents at Hephata. Couples, who were already together, spoke openly of their desire to move in together. In a couple of cases, these wishes could be fulfilled as outside living groups were established. To allow a couple to live together within the institution was too delicate of an issue for the administration of that moment.

In one case, a very aggressive woman was allowed to move into a house which was exclusively occupied by men. In the past she had continually had violent arguments with the women in her group. She

reacted very well to the men on a comrade-like basis. The men valued her tomboyish manner and the supposedly unconquerable behavior problems disappeared without a trace.

As the new residential houses were being planned, in order to relieve the pressure on the old premises, the members of the AG Pe Be work team attempted to assure that it would be possible to have mixed groups there. During this planning, the administration stressed again and again that it could not even consider such a drastic measure. It was however accepted that they must as well plan for the future. The new houses could not be left to be outdated in a short period of time. Three years later, the houses were then finally dedicated. All groups had residents of both sexes. In the meantime, this seems to be normal. No one gets upset about it anymore.

2.1.3. Positive developments and open problems

At the present time, about half of the residents live in mixed-sex groups. It can be generally observed, that when men and women live together, fewer behavior problems occur. All pay more attention to looks and cleanliness. Their manner has also become friendlier. A lot of friendships have developed. Still only very few couples have the desire to live together like husband and wife. The fact that the number of mildly retarded persons who live in institutions is decreasing has something to do with it. More and more, institutions are becoming occupied with the so-called severely retarded. Since the interest in genital sexuality decreases according to the severity of retardation these people are not interested in a marriage. Even the mildly retarded residents seem to be slow in this regard. They think about it a long time before they choose a partner. Changing of partners occurs very rarely. What the skeptics foresaw did not occur in any case. Sexual chavs had not broken out since making living together more normal was attempted. The advantages seem to outweigh the disadvantages.

Naturally there are still a number of unsolved problems. Sometimes a friendship goes into pieces. In some cases, one partner takes advantage of the other. The problem of contraceptives has not been solved optimally. Some couples want to have children and it is hard to know how to go about fulfilling their wishes. Homosexuality and masturbation are decreasing but obviously have not disappeared since mixed-sex group living was introduced. In spite of that, the institutions which took steps towards liberalization and normalization are convinced that what they have done is good and worthwhile

continuing.

2.2. Synopsis: Six Conclusions

The previous comments in the first part and the observation of the example of Hephata, can be summarized into the following six points.

1. Sexuality in a broad sense belongs to a fulfilled life.
2. The fear of excess and aberration is mostly unfounded.
3. Sexuality education must be regarded as an integral part of total education.
4. Persons who are mentally retarded must be prepared for life in a bisexual world.
5. Appropriate living arrangements must be found according to the possibilities and to the desires of individuals.
6. Important decisions should be discussed with those involved as much as possible.

The following deals especially with points three to six.

2.3. Sexuality education - an integral part of total education

This education begins with birth of a handicapped child. Parents often ask themselves if they must alter the way in which they previously lived. Precisely on the subject of sex, they feel uneasy. Many mothers and fathers ask themselves if they must turn prude.

In a letter to the editor, of the magazine "Zusammen", a mother writes (Kentler, 1985, 46): "We have a very large yard and our older children used to run around a lot, earlier, in the nude. My mother then demanded that they should at least wear a pair of pants. She had experienced as a child, in the small town in which she grew up, a situation in which a mentally retarded girl was teased and when she came into puberty, was sexually misused by half of the young men in the town. My mother wants to protect our daughter, Bärbel, from such a fate. She should not even know that there is such a thing as sexuality, if at all possible. My mother fears as well that Bärbel's sexuality will be uncontrollable once it is awakened. Earlier, my husband and I used to bathe naked with the children. We always snuggled up with the children. Should we allow this not to happen any more?"

A simple rule of thumb in answering this question would be the following: All of the principles that are seen as right in teaching normal and healthy children about sexuality, should also be

followed when dealing with children who are retarded. A family therefore, should not change all of its behavior as soon as a retarded child is born into the family. The changes would unnecessarily cause the normal children to feel insecure. It can only be viewed as an advantage for a child to grow up in a family which can act so naturally.

With no child can sexuality education be achieved by a single act of explanation. (like the motto, now it's time for mom to teach about the birds and the bees) Sexual education always means staying in communication with one another.

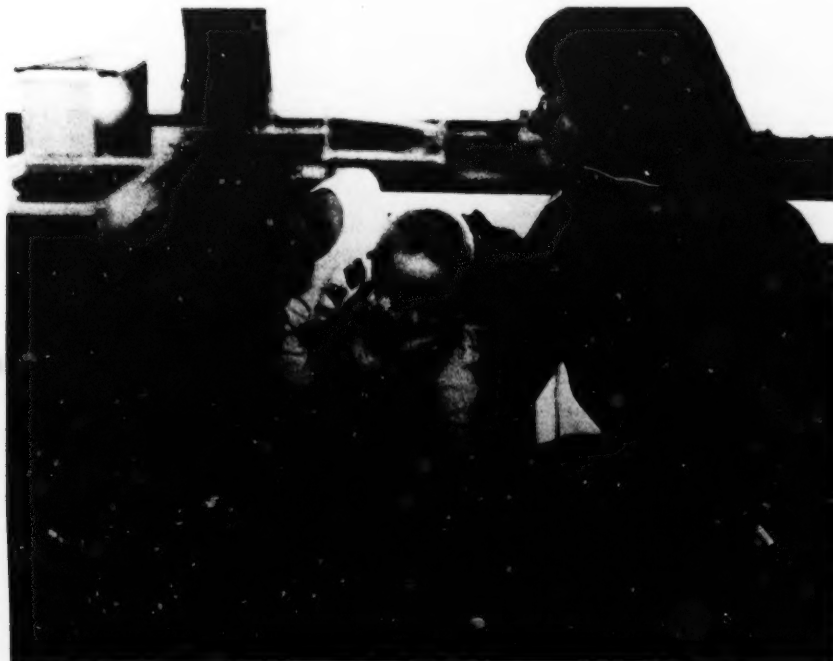
In the meantime, things have developed so liberally in Europe, that it is rarely possible to conceal anything from the children. Respected magazines advertise contraceptives. Details of intimate affairs are widely spread throughout the media. Worried parents question themselves more and more often, if their children will be able to overcome this flood of impressions without damage. Many fathers and mothers jump ahead of this and try to show their children their ideas about such things as early as possible.

With children who are mentally retarded, this is not possible to the same extent. Most can not read. Their lack of cognitive ability makes it more difficult to gain and process information. This, on the contrary, easily tempts the parents to leave their children in a condition of innocence. The handicapped sons and daughters become regarded as eternal children.

2.4. How do I explain it to my child?

This is the title of one of the first books about the facts of life for normal children (German title: Wie sag ich's meinem Kinde?) How do I explain it to my child, however, is asked by parents of handicapped children as well. Sexual education as an integral part of the total education and should start early, 'even' when children who are mentally retarded can not speak at all or can only communicate to a limited extent. The following are suggestions which can be carried through to help in this regard.

Before they enter puberty, children who are mentally retarded should know something about the following areas.



Sexuality education in a natural environment

2.4.1. Body image

It is obvious that we teach children that they have a nose, mouth, eyes, hands and feet. The pupils should get to know their own bodies and the appropriate words which are connected to the respective

parts. The excretory and sexual organs are often left out of such lessons. This should not be. Younger children occupy themselves unembarassingly with these body parts just as they do their mouth, eyes, and nose.

In the family there are many opportunities to teach something about these areas, such as bathing, changing clothes, and toilet training. When it is customary in a family for children and parents to bathe together, the child has the natural opportunity to get to know what the bodies of adults and the opposite sex look like.

In the school for the mentally retarded, the sand and water area gives a child opportunities to heighten his awareness of body image. The children find much joy in playing naked in the sand and painting their bodies with colored paints and then observing themselves in a mirror. A gigantic bubble bath is the height of pleasure.

2.4.2. Appropriate behavior

On one hand we try to teach to children that they should be unembarassed about their bodies and that it is acceptable to touch. On the other hand they must learn that there are certain societal rules to which they must adapt. Children must learn to differentiate between situations and learn what is and is not appropriate. Those behaviors which are accepted in the home and school environment, may not be allowed in public transportation and with strangers. Cuddling is fine with a mother, a friend, and a teacher. They must learn to hold strangers at a distance even if they are very friendly.

The important thing is this, children should learn to find joy in their own bodies. They must also learn however, that there are societal rules which must be followed. We, as nonhandicapped persons, can help make this process easier. I myself have often experienced a situation in which a mentally retarded child hugs a stranger, asks for some candy, and has success. When I would later question these people about their behavior, they typically would reply, "Oh, it doesn't matter, I couldn't turn down such a poor little guy." This falsely understood pity leads without fail to a behavior which can not be tolerated by adults who are mentally retarded. They are deemed as sexual maniacs when they touch a woman on the breast or as filthy, impudent, or suffocating.

2.4.3. Knowledge of pregnancy and birth

The fairy tale about the stork has had its day. Young children, who are mentally retarded have difficulties to understand, the

events which lead to pregnancy and birth of a child. Therefore when at all possible, children should be allowed to experience first hand within their family or circle of friends, how a baby grows within the mother's womb. The child can then take part in the preparations for the baby's birth and should be allowed to visit the baby as soon after its birth as possible.

2.4.4. Preparing for puberty

When children grow up with parents in a relatively open atmosphere, they will rarely wonder about the changes in their own bodies. Just the opposite in fact, they will be excited about growing into an adult. It is important to regard these changes as positive. Instead of saying, "Oh, how sas my little girl is getting bigger," we should rejoice with her and say, "Super! you have grown a little bit more." As a mother or father, one can look at secondary sexual characteristics with great worry and foster a thousand problems between themself and the child. This does not help the child at all. It is essential for developing a sense of self-worth for boys and girls when their parents help them by showing joy and pride in their development.

A girl should be prepared for the onset of menstruation. It is easiest, when a trusted female reacts normally and in an unembarrassed manner about her own period. I discovered this coincidentally with my own two sons as they were still quite young. I had always left my box of tampons in the bathroom without thinking about it. One day they invented the mouth-game. They would fill up the sink with water and throw one tampon after another into the water. The swelled-up tampons really did resemble mice. The children had a lot of fun. I found the whole ordeal a great waste but did find it then simple to explain what the tampons were used for.

Children who are not mentally retarded do not usually invent such creative games. If the mother is not embarrassed, she could let her children watch her as she changes her tampon. If she finds it uncomfortable she must find another way to convey this information. Especially in this regard, too much should not be forced on a mother. The children recognize when one is ungenthine and then nothing is gained anyway.

If the young girl is able to understand language, then the mother or trusted female can attempt to explain things to her. Tampons and sanitary pads should be made available as demonstration material.

It is more difficult when understanding and power of imagination are not fully developed, so the way to explain such things should be carefully thought out beforehand. In this case, a mother should observe her daughter well, so that she will be there for her first period. Through body contact, stroking, and a friendly manner of speech, she can show her that everything is not so bad, but instead totally normal. She can then teach her daughter how to keep herself clean and how to use sanitary pads and tampons.

For girls who are only mildly retarded, it is possible to explain to them the connections between menstruation and pregnancy. Pictures and schematic diagrams can be used to help them better understand.

2.5. Literature about the facts of life for youth who are mentally retarded

There are different kinds of publications for the sex education of mentally retarded. Yet there is still more helpful literature that has to be developed. And one of the problems is to find a good way of illustration.

Last year the Lebenshilfe in Austria, an organization of parents with children who are mentally retarded, has been publishing a book on that matter. In its text it is informative, yet in the pictures it still could improved.

On the following pages I am giving two examples of such publications in English. The first one is entitled

"Sex Education for the Developmentally Disabled: A Guide for Parents, Teachers, and Professionals, by Henry L. Fischer/Marilyn J. Krajicek/William A. Borthick, Baltimore/London/Tokyo: University Park Press Second printing, revised, 1974. 59p.

It is more fact-oriented. I am giving two examples on pages 22 and 23. Another publication is the following one:

Why Not? Sex Education of the Mentally Handicapped, by Lise Aubertin/Ara Dakessian/Jacques Moley, Montreal/Canada: Riviere-des Prairies Hospital 1978. 53 p.

It takes more into consideration the questions of feelings and relationship involved. I am giving three examples on pages 24 to 26.



PICTURE NO. 10 (Embracing)

1. What are these people doing?

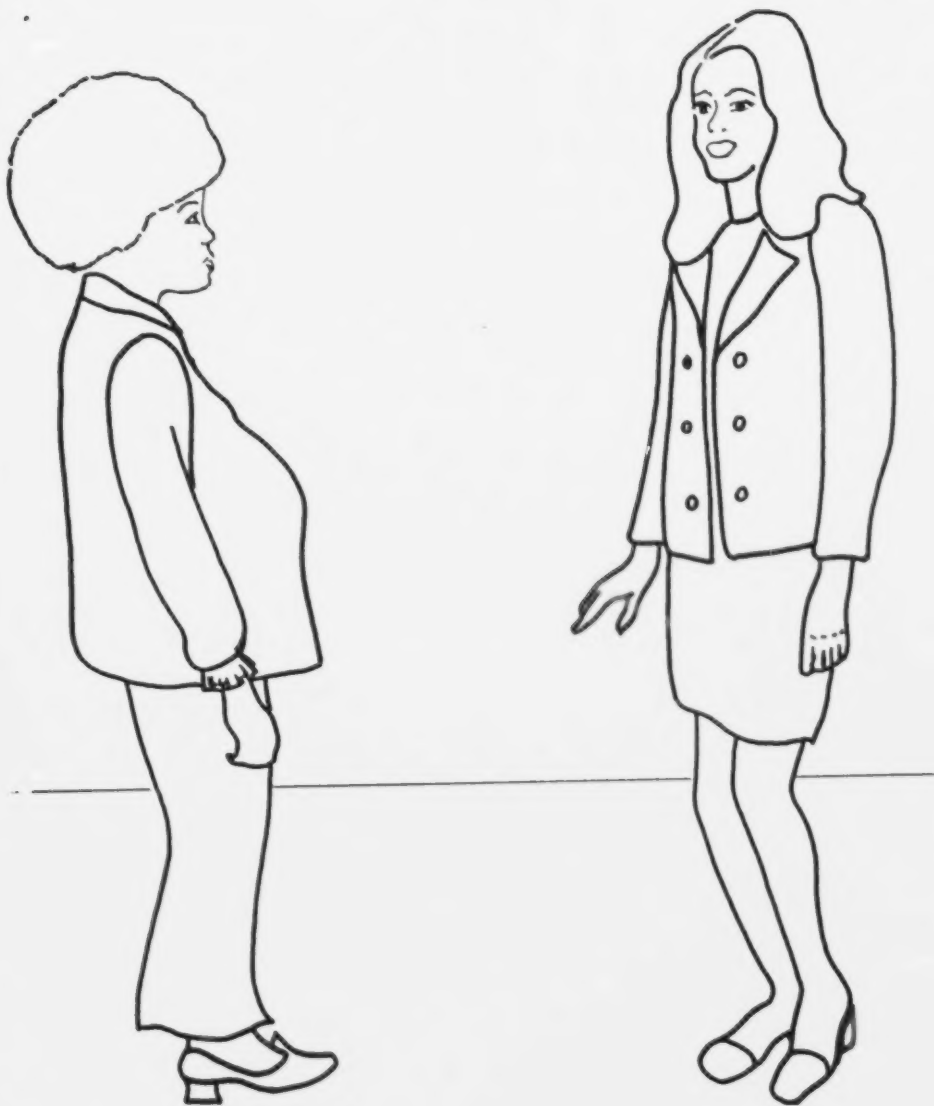
2. What do you call it?

(After client's response, ask . . .)

Why do people do this?

INTERVIEW HINTS

Accept "hugging" or "kissing." This picture and the one on the following page can readily give rise to a discussion of love and affection in general. It can also lead to distinguishing with the client the ways of expressing affection that are appropriate depending on how close the relationship is with the other person.



PICTURE NO. 18 (Pregnant and Nonpregnant Women)

2. Which of these two women is going to have a baby?
(After the client points, ask . . .)
 How can you tell?

INTERVIEW HINTS

The client will usually point correctly and indicate that he/she can tell because one lady is "fat" or has a "big stomach." This presents an opportunity to extend the discussion of question No. 1 on the preceding page. It is also important to emphasize the progressive growth of the fetus resulting in the increased size of the mother's body and the eventual need for the baby to come out. It may also be helpful to have the client estimate the size of a newborn baby.

3. How does the baby start to grow in the mother's body?

INTERVIEW HINTS

If the client has been able to respond with any certainty and appropriateness to the picture representing intercourse (page 28), he/she will probably give a similarly appropriate response here. This question more than any other may very likely make evident the client's misinformation about pregnancy and birth. Here again, it is critical to determine whether the client is actively interested in hearing more detail about how the baby starts to grow in the mother's body. If it is clear that there is little or no interest or awareness, move on to the next question. If interest is apparent, a sample explanation might go as follows:

"When a man and a woman love each other very much they sometimes show this love by lying very close to each other. When they do this, the man sometimes places his *penis* (review the term if necessary) into the woman's *vagina* (review). When this happens, a sticky white fluid comes out of his penis into the woman's vagina. This fluid has many very tiny seeds that we call *sperm*. In the woman's body there is also a very tiny seed we call an *egg*. When one of the man's sperm joins together with one of the woman's eggs, a new baby starts to grow. It grows in the part of the mother's body we call the *uterus* until it's ready to be born."

4. How long does a baby have to grow inside the mother's body before it is ready to be born?

(INTERVIEW HINTS on this question on page 43)

(Sex Education, pp. 24/25)

ANTOINE:

"It's so nice being with you.
You're pretty and when I'm with
you I want to touch you."



The Role of the Adult

Erotic behaviour at dances and in other social situations for instance, indicates that the time has come for the adult to assume his role as sex educator.

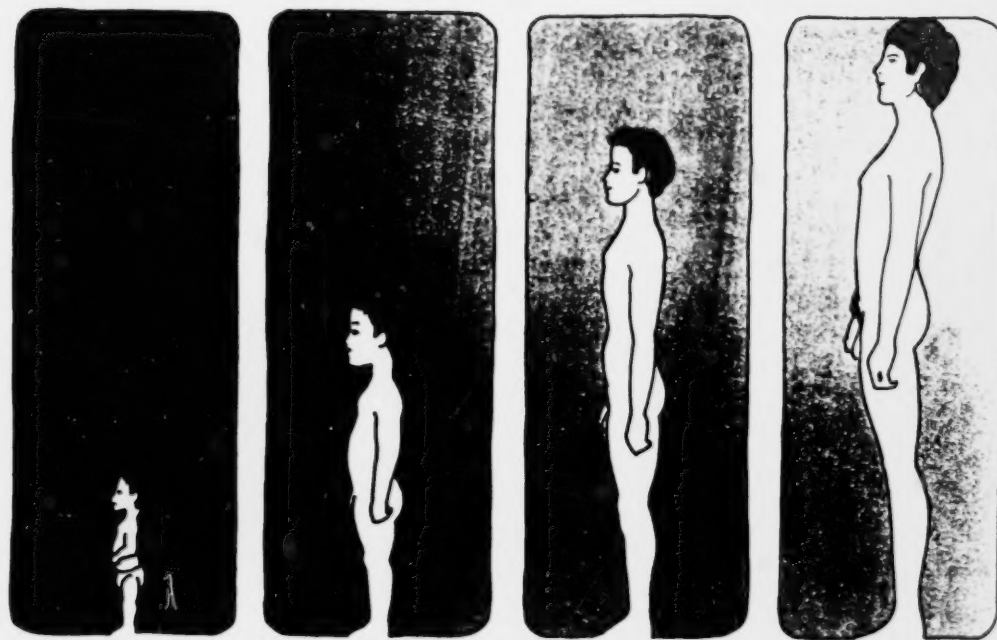
The adult must broach the subject as delicately as possible. He must help the adolescent to verbalize his emotions and understand what motivates him, for example, to choose the same dance partner.

The mentally handicapped must be made to feel that it is perfectly normal to be attracted to a member of the opposite sex. They must, however, also be taught that certain rules and norms of behaviour exist to prevent people's feelings from getting hurt.

(Why not?, pp. 14/15)

ANTOINE:

"I was a baby a long time ago.
I grew up and became a big boy.
Then I began to grow hair on my
face, under my arms, on my legs
and around my penis. My voice
also changed. Now, I sound more
like my father."



The Role of the Adult

We have a tendency to treat the mentally handicapped like young children. They, as a result, often live up to our expectations by remaining dependent and, in effect, deny their own adulthood.

The male handicapped adolescent is quite capable of distinguishing between an infant and a grown-up. The adult must therefore help the adolescent to realize that he too is becoming a man and that shaving, masturbation and love making are only signs of his adulthood.

(*What not?*, pp. 16/17)



ANTOINE:

"I come to see Diane right after work. I enjoy being with her."

DIANE:

"We eat, play cards, go to work and go swimming together. Wouldn't it be wonderful if we could live together and see each other more often!"

The Role of the Adult

Boys and girls realize through their contacts with one another that a complementarity exists between the two sexes.

As they mature, they learn to establish relationships founded on affection, tenderness and love.

Coming to terms with one's masculinity or femininity is a lifelong learning process. Sex plays a central role in the growth and development of the human personality and is an inseparable part of life from the very moment we are born. To deny or suppress sexual feelings is a denial of a very basic fact of human life.

Sexual urges are not something to feel guilty about or ashamed of. Rather than repress such feelings, we must learn to deal with them on a more human level — openly and honestly.

Sex is an instinct. However, in order for it to grow and develop into a meaningful, lasting and pleasurable relationship, sex must be accompanied by feelings of love and tenderness.

(Why not?, pp. 28/29)

Literature

- Adam, H. (1977): Curriculumkonstruktion für Geistigbehinderte. Eine Untersuchung zu Theorie und Praxis in den USA, unter besonderer Berücksichtigung des Normalisierungsprinzips. Marburg: Marburger Forschungsstelle für Vergleichende Erziehungswissenschaft 1977.
- Adam, H. (1985): Im Gespräch bleiben, in: zusammen: behinderte und nichtbehinderte Mitmenschen. Vol. 5, 1985, No 6/7, p. 42 f.
- Bundesvereinigung Lebenshilfe für geistig Behinderte (Ed.), Geistige Behinderung, Partnerschaft, Sexualität. (Schriftenreihe Lebenshilfe Bd. 2). Marburg/Lahn 1976.
- Fischer, H.L. / Krajicek, M.J. / Borthick, W.A. (²1974) Sex Education for the Developmentally Disabled. A Guide for Parents, Teachers, and Professionals, Baltimore/London/Tokyo: University Park Press 1974.
- Grossmann, H.J. (Ed.): Manual on Terminology and Classification in Mental Retardation (AAMD Special Publications No. 2), Baltimore: AAMD 1973.
- Grossmann, H.J. (Ed.): Classification in Mental Retardation, Washington, D.C.: AAMD 1983.
- Huber, N. (1975) Geschlechtserziehung bei geistig Behinderten., in: N. Huber / G. Katz, Geschlechtserziehung bei geistig Behinderten. Freiburg: Verband katholischer Einrichtungen für Lern- und geistig Behinderte 1975, 11-36.
- Kentler, H. (1985): Sollen wir prude werden? in: zusammen: behinderte und nicht-behinderte Mitmenschen. Vol. 5, 1985, No 6/7, p. 46f.
- Sporken, P. (1980) Sexualerziehung geistig behinderter Menschen, in: Sporken / Jacobi / van der Arend, Die Sexualität im Leben geistig Behinderter, Düsseldorf 1980, 11-49.

ETHICAL ISSUES

CONCERNING

MENTALLY HANDICAPPED PERSONS

by

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ETHICAL ISSUES CONCERNING MENTALLY HANDICAPPED PERSONS

A) AN INTRODUCTION

1) Recently, in rapid succession, a number of tragic incidents involving mentally handicapped persons have been reported in Hong Kong newspapers. I quote at random from the articles:

"A two-year-old boy who had been playing happily near his home was later found to have plunged 26 floors to his death...A nine-year-old girl, believed to be mentally retarded, had earlier been reported missing from a near-by children's home and was arrested ...It is understood the girl will be detained overnight pending a psychiatric report and advice from the Legal Department." Another English-language newspaper relates the same story this way:

"A mentally retarded girl was detained by the police yesterday in connection with the tragic death of a two-year-old boy, who plunged 26 floors...the arrested girl, 9, was helping police with their inquiries...the arrested girl...is believed to be an inmate of the...Children's Training Centre for the retarded nearby..."

A day later, a follow-up article stated:

"A nine-year-old mentally retarded girl arrested in connection with the death of a two-year-old boy...was sent to the Matauwai Girls' Home yesterday for psychiatric tests."

On the same day and in the same newspaper, but on a different page,

was a headline:

"Retarded Woman Comes Under SWD (Note: SWD = Social Welfare Department) Protection."

It was the story of a 23-year-old "mentally retarded woman who was made use of as a prostitute." "She was found as a hostess in a one-woman brothel and she also had contracted venereal disease because she received too many customers." The woman earlier was "convicted of theft and was sent to a correctional institute."

Essentially, these are the main points of the article.

2) Another newspaper item, published not long ago in a national paper in the United States, quoted a leading U.S. Government Education Department authority as saying: "A person's physical disability

and other 'external circumstances' are tied to his or her level of 'spiritual development'."

3) "Worker 'Satiated lust' On Mentally Ill Woman" is another headline appearing recently in Hong Kong. The article begins: "A 48-year-old construction site worker was jailed for two years yesterday...for seducing a mentally retarded woman."

4) Horrific are the ethical conclusions to be drawn from statements made by professionals and experts who claim that with the knowledge available today in using the process of amnio-centrisis, "we can now rid our population of all defectives." Is this not a repetition of what Hitler attempted to do in years when he boasted he was "forming a pure race"?

5) Ethics---moral norms---is the essential element used to make proper judgements concerning these cases, and other issues as well. For example, the issues of "Right to Life," euthanasia, the "quality of life" and choices pertaining to it (a theme clearly elucidated by Professor Peter Mittler in a lecture to the British Psychological Society, 1 April 1984).

Ethics is the basis of justice, rights, parental and professional decisions and the role of the handicapped in making these decisions, neglect and sexual abuse cases, and obligations of the family, society and international groups.

6) I feel, with a deep conviction, that international, regional and national convocations centering on and actually including the mentally handicapped persons should recognize and should present some definite guidelines, some basics, some pathways in ethics (moral norms) applicable to the existence and human development of the mentally handicapped. We hope to initiate such interest and some positive action in this regard through this paper.

B) A FOUNDATION

1) My background, my education and experience have been as a Christian, and as a Catholic priest. Therefore, what I express here is a development from that educational background and twenty-six years involved in ministry and social service activities in Asian

lands, and within Asian societies.

2) Ethics is a philosophy or system of moral norms.

Ethics is conforming to the right principles of a given moral system. It is fundamental in choosing right or wrong---good or evil.

Ethics indicates that there are objective norms of conduct dealing with human actions.

Ethics is the basis for the "self-advocacy and the chance to choose" which Professor Mittler advocates in his lecture mentioned earlier.

Ethics is based on a clear distinction between what are called "human actions" and what are called the "acts of man." Human actions are actions of choice, and carry with them distinct rights and responsibilities. They are governed by sanctions (laws). Acts of man are activities characteristic of humans, but not under the direct control of the person. For example, body metabolism, circulation of blood, etc.

3) I digress for a moment, at this point, to formulate for your mind's eye a framework wherein ethics relates to the nature of human society.

- a) We recognize that human society is certainly an entity in itself. Society acts independently of the individual. We, as individuals, are subject to society. States and nations ---human societies---endure beyond the lifetime of people.
- b) However, people are the ultimate constituent of all human social existence, and therefore the ultimate purpose of human society is to serve the ends---the purposes; that is, the good---of people.
- c) We readily recognize that, in human society, history reveals the existence of many and varied "Isms"---expressions of human society. We mention an example or two:
 - i) "Individualism"---a society in which the individual and his or her norms and goals are the sole end (purpose) of human existence.
 - ii) "Collectivism"---a society in which the collective norms and goals are considered to be the ultimate and legitimate good of human existence.
- d) Many of you know well that the concepts of the nature of man, of the nature of the state, of the order of society, etc.

have been pondered by thinkers in every era, beginning with the first days of the human race. A litany of philosophers and learned persons in the East and West (including Aristotle, Confucius, Kant, Hegel, Marx, Bergson, Weber, Toynbee, to name a few) have, over the years, sometimes enhanced and sometimes complicated teachings concerning ethical matters.

4) That a moral consciousness (that is, a knowledge of good and evil) exists is the experience of all people, and this "all people" includes the mentally handicapped persons.

"Good" is the fulfilling, perfectly or imperfectly, of the functions which are characteristic of a specific being.

"Evil" is the non-fulfillment of those functions.

5) The principle (criterion) of moral norms for all people must afford:

- a) The means for discerning, in general, what kind of conduct is morally good or evil in human society.
- b) The means for determining the moral relevance of acts in particular situations of human society.
- c) The means for deciding conflicts of duties about the right line of conduct of human society.

6) Moral norms always present themselves to the individual as something particular. Conforming to those norms (laws) gives each of us dignity as a person, and exemplifies the rights and responsibilities of each individual.

Human nature's fundamental impulse is to act according to "right reason" (called "love" in a philosophical sense).

Laws, in the sense of norms---moral consciousness---of morality, do not mean legal or civil jurisprudence only. They do mean natural laws, laws of conscience.

The principle of moral norms (or laws) recognizes that all laws necessitate proper sanctions and imputability. Necessarily, in ethics then, correct norms for the legislator and for the subject are required; and must be promulgated. There must be proper interpretation of laws, and a disciplined formation of conscience.

These basic principles make questionable so-called "situational ethics"---an ethical system based solely upon subjectivity.

7) The moral quality of our human actions derives from three different sources...each so closely connected with the other that unless all three are simultaneously good, the action performed goes against "right reason" and becomes evil.

These three sources are:

- a) The object of the human act must be good. (For example, taking another's possessions with permission is a good; taking the same possessions without permission is stealing, an evil.)
- b) The attending circumstances are distinct from its object, and can alter the moral tone of any human action. (For example, injuring a person who is attacking you and injuring an innocent person wilfully.)
- c) The purpose---end---also affects the morality. We know from common sense that "the end does not justify the means." (For example, Hitler's intent to have a "pure race" by eradicating the handicapped, disabled and certain ethnic groups by inhuman torture and genocide.)

C) AN APPLICATION TO THE MENTALLY HANDICAPPED PERSONS

1) People, all people including mentally handicapped persons, are moral agents. The mentally handicapped person, as a human person, has rights and duties because he or she has the universal right of choice and self-advocacy. These are human rights, and not rights given or taken by the state or other persons.

2) The mentally handicapped person is a rightful member of a family, of a community, and of a society...again, a natural right in all cases.

3) Acknowledging the existence of these human rights, and within proper ethical norms, the United Nation's General Assembly proclaimed (on December 20, 1971) in a document on the Rights of the Mentally Retarded Persons the following:

- a) The mentally retarded person has, to the maximum degree of feasibility, the same rights as other human beings.
- b) The mentally retarded person has a right to proper medical care and physical therapy and to such education, training, rehabilitation and guidance as will enable him or her to

develop one's ability and maximum potential.

- c) The mentally retarded person has a right to economic security and to a decent standard of living. He or she has a right to perform productive work or to engage in any other meaningful occupation to the fullest possible extent of his or her capabilities.
- d) Whenever possible, the mentally retarded person should live with his or her own family or with foster parents and participate in different forms of community life. The family with which he or she lives should receive assistance. If care in an institution becomes necessary, it should be provided in surroundings and other circumstances as close as possible to those of normal life.
- e) The mentally retarded person has a right to a qualified guardian when this is required to protect his or her personal well-being and interests.
- f) The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. (On this point, please recall the Hong Kong cases mentioned at the beginning of this talk.) Now, to continue in the words of the United Nations' document: If prosecuted for any offence, he or she shall have a right to due process of law with full recognition being given to his or her degree of mental responsibility.
- g) Whenever mentally retarded persons are unable, because of the severity of their handicap, to exercise all their rights in a meaningful way or it should become necessary to restrict or deny some or all of these rights, the procedure used for that restriction or denial of rights must contain proper legal safeguards against every form of abuse. This procedure must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subjected to periodic review and to the rights of appeal to higher authorities.

4) Later, in another United Nations' Declaration on the Rights of the Child, guidelines are expanded even more to ensure the rights and protection of the mentally handicapped for normal lifestyles and human development.

D) THE ISSUES

1) We preface our consideration of some specific moral issues pertaining to the mentally handicapped persons by calling attention to the fact that ethics itself bears a close relationship to social criticism and social reform. This fact has a particular bearing on attitudes, laws and issues concerning the world's mentally handicapped.

Ethics---moral norms---is a practical, not a speculative, discipline of philosophy. Its object is not to acquire knowledge for its own sake, but to inform and to form people in a framework of fundamentals of moral consciousness on which to build a just and correct personal and social life.

The final object of social ethics is the application of these right principles to the manifold phenomena of actual human society ---a human society with mentally handicapped persons incorporated in it as legitimate members.

2) I touch now on the so-called "Right of Life" issue. This matter is widely argued in many lands today, and it is especially pertinent in population-control movements, and in legal and political controversies.

The term "abortion" as understood in our (Catholic) moral norms means expelling an immature fetus from the mother's womb. I do not propose that this is the proper time and the proper place to fully expound on this subject, but it is the core-issue, I well suspect, that prompted Professor Mittler to present this question in the lecture I referred to earlier. Mr. Mittler said:

"The first point I would like to single out concerns that assumption that some people are so severely handicapped that their lives cannot be worth living and that they are better off dead...Whether such a statement can morally or logically be made by one human being about another can be debated on philosophical grounds. My concern here is with the professional judgement involved. How far can a doctor make predictions about the future personal and social development of a baby with a handicapping condition?"

Pertinent to Professor Mittler's query, might I add a word about a television program I saw just recently. A great revelation to me; startling and bearing directly on the right to life issue.

The program concerned three children---two boys and one girl---

born in England. All three were victims of hydrocephalus. It was presumed that their life spans would be short ones. However, thanks to the ingenuity of a local doctor, a small tube was inserted into the cranial cavity and the life-threatening fluid was drained off into the body. All three persons are about 20 years old today... What has startled the medical profession is that the very small segment of brain tissue each person has seems to have taken over functions normally carried out by tissues that are non-existent! Not only are these three people functioning normally, but all three seem to be geniuses in their fields of study (biology, computer data, etc.)!

What would have resulted to these three people if they had been conceived in our times and their "defectiveness" determined by amniocentrisis? In hoping to rid some societies of "defectives" are we not depriving the same societies of geniuses...contributors to society? Where stands morality...right reason?

3) Now, touching upon the rights of all human beings to the basics of life---the essentials: food, clothing, shelter, love, etc. ---and decisions concerning them, I refer once again to the United Nations' proclamations pertaining to the Rights of the Mentally Retarded Persons. There are statements about human rights and declarations about the rights of disabled persons.

Are these documents---specific statements of moral norms---actually morally binding on all of us?

What about the sanctions involved?

There is much evidence that civil authorities and courts in many nations have upheld these norms as presented. (Note: The compulsory education law of Japan.)

There exists a still greater need for more serious discussion and clearer decisions in these matters by all of us here, who aspire "to grow in wisdom" concerning mentally handicapped persons.

4) It is most encouraging to see in education and labor matters a continuous development of international and national level legislation. This legislation has fortified the rights of the mentally handicapped to have not only the availability of a proper education and training, but also guidance which will enable them to develop their abilities and to achieve their maximum potential.

Ethics, concretized into civil laws, is helping handicapped

persons themselves to voice their own position concerning human rights. This is being done through their own organizations and means of advocating pertinent local laws to ensure their natural human rights.

Enthusiasm is also evident in places---perhaps there could be more in number---in regard to ethics and human labor. In a limited number of Asian nations, there is a solidarity among handicapped people to achieve their due rights, and to be able to perform productive work and engage in meaningful occupations to the fullest possible extent of their capabilities.

Unfortunately, while these advances---limited though they may be in many respects---are taking place more rapidly in developed countries, there remains a noticeable lack of knowledge of these rights and/or recognition of them in so many developing nations of Asia. There is a long, long road to walk in fulfilling the educational needs of handicapped people and the societies that surround them.

5) And here, I only mention, in passing, the very serious issues of sterilization, marriage, inheritance and their relationship to mentally handicapped persons. Difficult moral decisions with widespread personal and social effects are involved in these everyday human actions.

Might I refer again to the words of Professor Mittler's lecture (at the University of Warwick, on April 1, 1984). He stated:

"I recently attended an international session of the (North American) People First organization in Canada which was discussing compulsory sterilization of mentally handicapped people ---still commonly practiced in parts of North America. It was felt the mentally handicapped people had the same right as anyone else to have children but that many needed help in looking after children and that it was up to the parents and the professionals to ensure that they should exercise choice in this matter."

"Right reason" is the proper basis of morality. In the matter of sterilization, would it not be proper to earnestly educate the mentally handicapped person as much as possible, and then solicit an opinion from that person concerning his or her own moral decision?

At a recent world conference pertaining to the mentally handicapped, a delegate from a Scandinavian country explained that by a

refined form of sterilization his country had "solved" the problem of mentally handicapped persons being born from mentally handicapped parents. I would be most interested in hearing about the ethical norms used by the authorities in his country to justify this practice...

Attitudinal surveys concerning mentally handicapped people, and, indeed, civil laws too, reveal a basic right of all people to inheritance. However, there is a definite ambivalence in people when it comes to the matter of actually involving a mentally handicapped person in receiving and/or distributing property. Again, it must be repeated, right reason and justice---according to moral norms---must be made to prevail in all human actions.

6) In this paper, I have touched upon only a few ethical issues, and in a very sketchy way. These matters rate much more rational discussions here and now and in international and local meetings in the future. It is the basis of the WHY of what all of us are here for!

E) A SUGGESTION OR TWO

1) I recommend the development of a better educational process and meaningful informational services available to the mentally handicapped relating to ethical matters, particular rights and associated responsibilities.

2) I encourage the development of proper means to deepen the active role of mentally handicapped persons in the decision-making role concerning their own vocations, skills, and choices in life.

3) I look to better informational services for parents and for the public concerning ethical matters and their application to the daily life of humans, and in particular to the circumstances of the mentally handicapped people.

4) I advocate a systematic plan to form properly correct public ethical attitudes through mass media means.

5) I encourage research, study, and discussions among responsible people concerning the application of norms of ethics to local

societies.

6) I suggest that concrete ways be found to eradicate ignorance, violence, fear, and imputable habits which violate proper norms of morality for mentally handicapped persons.

IN CONCLUSION

Ethical issues related to mentally handicapped people are, indeed, matters of life and death in certain circumstances. Proper ethics leads to proper moral consciousness in choosing to do right or wrong. There must be a growth in the wisdom, in the knowledge of the moral norms governing all of human society.

I end with Professor Mittler's words:

"They (these choices of a quality of life) are part of a continuum of decision-making affecting the quality of life available not only to disabled people, but to all of us."

(E N D)